

2nd Annual ASTHMA AND GENOMICS CONFERENCE



June 7, 2007

Utah Department of Health, 288 North 1460 West, Salt Lake City, Room #114

AGENDA

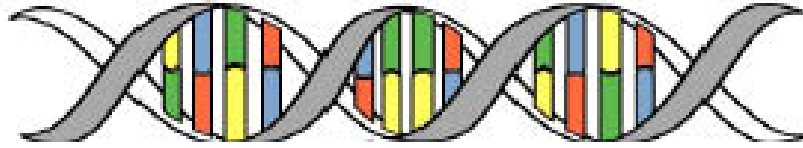
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| 8:00 – 8:30 a.m. | Registration and continental breakfast |
| 8:30 – 8:45 a.m. | Welcome and logistics |
| 8:45 – 10:00 a.m. | Healthy Homes University Project
<i>Using family history to identify and intervene with at risk asthma families in a low-income community.</i>
Karen Edwards, PhD
University of Washington Center for Genomics and Public Health |
| 10:00 – 10:15 a.m. | Break |
| 10:15 - 10:45 a.m. | Predisposition to Asthma Among the Utah Population
Craig Teerlink, PhD Candidate
Department of Biomedical Informatics, University of Utah |
| 10:45 - 11:45 a.m. | Genomics in the Clinic, A Panel's Perspective
Paul Eberle, RTT, PhD
Weber State University, Department of Respiratory Therapy

Tad Jolley, R.Ph.
Pharmacist, Jolley's Pharmacies

Wayne Cannon, MD
Primary Care Clinical Program Leader, Intermountain Healthcare |
| 11:45 a.m. – 12:00 p.m. | Closing Remarks |

* Although, attendance in person is STRONGLY encouraged, call-in and video-conferencing is available in some areas. Call 801-538-6141 to check availability.

Register online at: www.health.utah.gov/asthma/genomicsworkshop.html



background

Genomics is predicted to revolutionize public health and medicine as we know it today. The Utah Department of Health Asthma and Chronic Disease Genomics Programs have recognized the importance of preparing for the genomics era and have begun to explore how genomics can be used to better the understand and treat asthma.

History:

- 2001 – The Utah Department of Health receives funding from the Centers for Disease Control and Prevention (CDC) to form the Asthma Program.
 - Vision: Utah communities working together to improve the quality of life for people with asthma.
- July 2003 – The Utah Department of Health receives funding from the CDC to form the Chronic Disease Genomics Program.
 - Mission: To develop infrastructure and leadership capacity through education, data collection, and family health history interventions, to integrate genomics into public health and chronic disease prevention activities.
- September 2003 – The Utah Asthma Plan is unveiled. Genomics is included in one of the plan's objectives but stakeholders are unsure how to proceed with its implementation.
- April 12, 2006 – The 1st Asthma Genomics workshop is held. An asthma genomics work plan is developed as a supplement to the Utah Asthma Plan.
- November 2006 – A portion of the Utah Genomics Plan is released, which contains 8 goals to address integration of genomics into public health activities. Members of the Utah Genetics Advisory Committee and Family Health History Task Force begin work on implementing the plan.
- April 2007 – The new 2006-2012 Utah Asthma Plan is unveiled. The plan contains one genomics-related objective and 13 strategies.
- June 7, 2007 – The 2nd annual Asthma Genomics workshop is held. The goal of the workshop is to continue integration of the asthma genomics work plan and provide training to stakeholders on how genomics will impact asthma treatment and management.



2007-08 Utah Asthma Task Force Priorities

Asthma Friendly Pharmacies

The Utah Asthma Program and Utah Asthma Task Force will work with community agencies to develop an asthma friendly pharmacies program that will improve continuity of care, assist physicians with patient education and provide patients with additional resources for asthma management. The Utah Asthma Task Force will coordinate with interested partners to develop and implement this program statewide.

Emergency Department Discharge Program

Develop an emergency department discharge program to improve follow-up visits and provide resources for patients that are treated and released in EDs or urgent care facilities. Coordinate with hospitals, and emergency departments to educate staff on proper asthma discharge protocol to improve asthma management and continuity of care upon discharge from these departments.

Train/educate provider support staff

Develop asthma training and resources for provider support staff to assist physicians in patient education, disease management, improving follow-up visits, and monitoring symptoms. This project stems from the *Provider Resource Manual* and the Chronic Care Model philosophy stating that asthma care needs the participation of an entire health care team. The Utah Asthma Task Force will coordinate with hospitals, long-term care facilities, home care agencies and clinics to provide continuing education credit, and in-service hours to support staff concerning asthma.

Asthma Health Care Provider Manual

Continue to market the *Utah Asthma Health Care Provider Manual* to increase utilization of the manual and use of the NAEPP guidelines. The task force will provide updates from the new NHLBI guidelines to physicians and to those that previously requested the manual.

Public Awareness Efforts

The Utah Asthma Program will use several strategies to increase public awareness. 1) A user-friendly asthma web site will be updated at least bi-weekly to ensure current information. Web trends will also be monitored. 2) News releases about current events and the release of new programs will be developed and implemented in appropriate venues.

Community mini-grants

The Utah Asthma Provide will award 3-5 mini-grants to community organizations/groups to implement strategies from the Utah Asthma State Plan that address reducing asthma hospitalizations.

Asthma School Resource Manual and Training

Continue with current interventions for implementing the school resource manual and training to public, private and charter school faculties throughout Utah.

ALAU's Open Airways Training

Support the American Lung Association in implementing OAS in schools, a nationally recognized asthma education program that empowers children aged 8-12.

Winning With Asthma

Continue to implement the "Winning With Asthma," a completely online educational for coaches, physical education teachers, referees and anyone that works with youth athletics.

Child care efforts

Develop asthma training and/or resources for child care personnel to assist in creating asthma friendly environments for children with asthma at child care facilities in Utah.

Inhaler Law in Spanish

The inhaler law will be translated into Spanish and implemented by working with partners in the Hispanic community.

Home-hygiene Educational Materials

The home-hygiene educational materials will target reducing environmental triggers found in the home among the low socio-economic-status (SES) population.



Healthy Homes University Project

Using family history to identify and intervene with at risk asthma families in low-income communities.

Karen Edwards, PhD, University of Washington

Discussion question: (Please refer to the 2007-08 Utah Asthma Task Force Priorities). How do we address genomic risk factors (both genetic and environmental) in the Utah Asthma Task Force priority activities?

Notes:



Predisposition to Asthma Among the Utah Population

Craig Teerlink, PhD Candidate, University of Utah

Discussion questions:

How do we use this data to improve asthma care?

Notes:

What organizations would find this data interesting?

Notes:



Genomics in the Clinic: A panel's perspective

Facilitator will hand out the following set questions to audience members. We will then go through the set questions, after which time will be given for audience members to ask additional questions.

1. **(ALL)** How ready is your profession to use genomics...
 - a. To make clinical decisions in diagnosing and managing chronic diseases?
 - b. To use pharmacogenomics concepts to tailor or personalize medications and treatments to avoid adverse drug reactions?
 - c. To provide education and improve patient care?
2. **(ALL)** What are one or two recommendations you have to help ready your colleagues and future health professionals for genomic advances?
3. **(ALL)** What responsibility should public health play in helping to ready you as an individual and your profession to address genomics both currently and in the future?
4. **(Paul Eberle and Wayne Cannon)** How is family health history collected at your clinic? Is a family history of asthma routinely collected?
5. **(Tad Jolley)** Is it feasible for pharmacies to collect, document, and use family health history? Genetics information in general?
6. **(ALL)** Do providers receive an incentive for collecting family health history of chronic diseases? What types of incentives would encourage collection and use of family health history?

Facilitator will now read the following scenario:

A young couple has two children, ages 3 and 7. The family lives in south Davis County, close to the freeway and refineries. The youngest child has been coughing and wheezing irregularly for several months and the mother is concerned. The coughing intensifies at night. You see the child in your clinic and inquire about the child's symptoms, environmental risk factors, and medical history. The mother also causally mentions a family history of asthma. Upon further questioning, you learn that the child's father suffers from eczema and the maternal grandmother and maternal aunt have asthma. You diagnose the three year-old child with asthma and prescribe a long-term controller medication and an inhaler for emergencies.

7. **(Wayne Cannon)** In your experience, how often do parents raise concern of a family history vs. you having to elicit the history?
8. **(Paul Eberle and Wayne Cannon)** What education would you provide to this family?
9. **(Paul Eberle and Wayne Cannon)** How does knowing this family's health history affect the type of care you would provide to the seven year-old who has not been diagnosed with asthma yet?

Facilitator will now read the following scenario:

Going back to our scenario, let's imagine the seven year-old child has now been diagnosed with asthma as well. The mother receives a prescription for a long-term controller medication and takes it to her local pharmacy to get filled. Upon arriving, she realizes the prescription is for a different medication than what her three year-old child with asthma uses. She is concerned about starting the seven year-old on the prescribed medication because her three year-old had a bad reaction to this same medication. It took several rounds of trial and error with different corticosteroids before finally finding a medication that worked well.

10. **(Tad Jolley)** What role, if any, should the pharmacist play in helping to utilize family health history and pharmacogenomics information to avoid a possible adverse drug reaction in the seven year-old child?
11. **(Tad Jolley)** In your experience, does a family history of asthma impact patient compliance with taking medications?
12. **(ALL)** What ethical issues do you consider important with regards to using genetic information, such as might be obtained through a family history or genetic test?



Resources

Genomics

- Chronic Disease Genomics Program, Utah Department of Health
<http://health.utah.gov/genomics>
- Centers for Disease Control and Prevention (CDC) Office of Genomics and Disease Prevention <http://www.cdc.gov/genomics/>
- Asthma Genomics: Implications for public health perspective (CDC)
<http://www.cdc.gov/genomics/training/perspectives/asthma.htm>
- Genetic Science Learning Center <http://learn.genetics.utah.edu/>
- University of Washington Center for Genomics and Public Health
<http://depts.washington.edu/cgph/workinggroups/subhead.php?fid=24>

Asthma

- Asthma Program, Utah Department of Health <http://health.utah.gov/asthma>
- Allergy and Asthma Network, Mothers of Asthmatics
<http://www.aanma.org/breatherville.htm>
- American Lung Association <http://www.lungusa.org/>
- Asthma and Allergy Foundation of America <http://www.aafa.org/>
- National Heart, Lung, and Blood Institute <http://www.nhlbi.nih.gov/index.htm>
- National Jewish Medical and Research Center
<http://www.njc.org/disease-info/diseases/asthma/index.aspx>

Ethical Issues and Legislation

- Genetics and the Law, Council for Responsible Genetics
<http://www.genelaw.info/>
- National Conference of State Legislators <http://www.ncsl.org/index.htm#>
- Utah Genetic Testing Privacy Act
<http://www.code-co.com/utah/code/03/26-45.htm>

Can Genomics Explain Asthma Disparities?

New data reveal differences in asthma rates across Utah

(Salt Lake City, UT) – If you’ve ever thought there seem to be a lot of children and adults with asthma in your neighborhood, you may be right. New data from the Utah Department of Health (UDOH) show there are big differences in the rates of the disease from city to city, and even neighborhood to neighborhood in Utah.

The differences have led health experts to question whether genomics – the interaction between genes and the environment – may be at play. “Historically, asthma has been considered an environmental disease triggered by factors like air quality, dust mites, and tobacco,” said Libbey Chuy of the UDOH Asthma Program. “But with recent advances in genetics, it is becoming clear that asthma is caused by an interaction between both the environment and a person’s genetic makeup.”

Asthma data collected from 2003-2006 by the UDOH show several areas (neighborhoods or regions) with higher or lower reported asthma rates than the state average of 8.5%. The five areas with the highest rates among youth aged 0-17 are:

- South Ogden (12.9%)
- Riverdale (15.8%)
- Downtown Salt Lake (13.0%)
- Woods Cross/North Salt Lake (add 16.2%)
- Glendale (13.1%)

Source: *Utah Health Status Survey*

Karen Smith lives in North Salt Lake and believes the nearby refineries and processing plants have worsened her son’s asthma.

“My son returned to live with me in October 2006 and by November he was wheezing and coughing, enough so that I took him to a specialist,” said Smith. “I also called the

Page 2 of 2 – Can Genomics Explain Asthma Disparities?

management of our mobile home community and asked them to help clean up some of my environmental concerns,” Smith added.

Utah areas with the lowest reported prevalence of child asthma cases are:

- Bountiful (3.1%)
- Provo South (3.6%)
- Utah County South (4.0%)
- Lehi/Cedar Valley (4.2%)
- North Orem (4.6%)

Source: *Utah Health Status Survey*

Alissa Walker of Utah County wasn’t surprised when her nearly two-year-old daughter was diagnosed with asthma. “My mother-in-law and my husband’s grandmother both have asthma - it just runs in our family,” Walker said.

What is the difference between the Smiths and the Walkers? Why does it appear some individuals are predisposed to the disease and others are not? Exactly which environmental factors influence those living in these areas?

These and other questions are being discussed by health professionals across the state. On Thursday, June 7, 2007, the Utah Asthma Task Force will host the 2nd Annual Asthma Genomics Conference to discuss how genomics will impact the management of asthma in the future. The conference is free and open to the public, but online registration is required. To register, visit: <http://www.health.utah.gov/asthma/genomicsworkshop.html>. For more information on asthma, go to www.health.utah.gov/asthma.

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The mission of the Utah Department of Health is to protect the public's health through preventing avoidable illness, injury, disability and premature death, assuring access to affordable, quality health care, and promoting healthy lifestyles.



Glossary

- **Albuterol:** (Beta 2 agonist or albuterol sulfate) The most commonly seen rescue or quick relief medication used to relieve asthma symptoms quickly by relaxing muscles around the airways. Also used before exercise to prevent asthma symptoms for people with exercise-induced asthma. Most often used as an inhaler or with a nebulizer.
- **Allele:** One of the variant forms of a gene. Different alleles may produce variation in inherited characteristics.
- **Allergen:** A substance which causes an allergic response in sensitive individuals. Allergens can be either natural (e.g., pollen, dust) or man-made (e.g., perfume, cleaning agents).
- **Alveoli:** Tiny air sacs where oxygen and carbon dioxide (a waste product) are exchanged. Oxygen goes to the body, and CO₂ is exhaled out.
- **Anti-inflammatory drugs:** Drugs that reduce the swelling and irritated tissues that are the symptoms and signs of inflammation.
- **Asthma:** A chronic, inflammatory disorder of the airways characterized by wheezing, breathing difficulties, coughing, chest tightness, and other possible symptoms. People with asthma have very sensitive airways that are constantly on the verge of over-reacting to asthma triggers.
- **Asthma Action Plan:** A written document that outlines an individual treatment plan for a person who has asthma; developed in talking with the health care provider, family member and caregivers. Effective action plans help patients control their asthma and live healthy active lives.
- **Asthma episode/attack/exacerbation:** A time when asthma symptoms flare up or intensify, requiring immediate adjustments in treatment and medication to get symptoms under control. Asthma episodes may occur suddenly, with few warning signs, or build slowly over a period of hours or even days.

- **Asthma management:** A comprehensive approach to achieving and maintaining control of asthma. It includes patient education to develop a partnership in management, assessing and monitoring severity, avoiding or controlling asthma triggers, establishing plans for medication and management of exacerbations, and regular follow-up care.
- **Atopy:** The increased likelihood (or possibility), usually because of genetics, that a person will develop allergic-type responses to common environmental allergens.
- **Attributable risk:** The excess risk of a specified health effect assumed to result from a specified exposure. In the case of complex disease, one can speak of the attributable risk associated with the genetic or environmental contributions.
- **Base pair:** Two bases, which form a “rung on the DNA ladder”. Bases are the “letters” (Adenine, Thymine, Cytosine, Guanine) that spell out the genetic code. Normally adenine pairs with thymine and cytosine pairs with guanine.
- **Bronchial tubes (bronchus):** The major airways of the respiratory system that carry air from the trachea (windpipe) to the microscopic air sacs (alveoli) in the lungs.
- **Bronchiole:** The smallest airways in the lungs.
- **Bronchoconstriction/ bronchospasm:** The tightening in the airways that occurs with asthma. Caused when the muscles around the bronchial tubes contract in response to specific triggers.
- **Bronchodilator drugs:** Drugs that relax muscles around the airways, which open the airways up. Some bronchodilators are used for quick relief of symptoms during an asthma attack. Others are taken every day to prevent symptoms.
- **Candidate gene:** A gene, located in a specific chromosomal region suspected of being associated with a disease, whose protein product is consistent with the known disease process.
- **Carrier testing:** Type of genetic testing that can tell individuals if they are carriers of a mutated gene. Carriers rarely develop the disease, but can pass on the mutated gene or the normal gene to their children (Example: cystic fibrosis).
- **Chromosome:** One of the threadlike "packages" of genes and other DNA in the nucleus of a cell. Humans have 23 pairs of chromosomes.

- **Complex trait:** A trait that results from the interaction of one or more genes and environmental factors (Example: asthma).
- **Confidentiality:** Acknowledgment that genetic information is sensitive and private and access should be limited to those authorized to receive it.
- **Controller medications:** The standard treatment of asthma for most patients who have “chronic” asthma and need daily medication. These medications provide “long-term relief” by making airways less sensitive which reduces symptoms before they even appear. Called a controller because it controls asthma and prevents asthma attacks.
- **Corticosteroid:** A type of medication used to reduce inflammation. These drugs mimic a substance produced naturally by the adrenal glands. In asthma, these drugs are often taken through an inhaler for long-term control. They may also be taken orally or given intravenously for a short time if asthma symptoms become out of control.
- **Dander:** Scaly or shredded dry skin that comes from animals or bird feathers. Dander may be a cause of an allergic response in some people.
- **DNA:** The organic molecules inside the nucleus of a cell that carries the genetic instructions for making living organisms.
- **Dry powder inhaler:** Similar to a metered dose inhaler except the medicine comes out of the DPI as a dry powder. The patient exhales out a full breath, places the lips around the mouthpiece, then quickly breathes in the powder.
- **Dyspnea:** Difficult breathing.
- **ELSI:** An abbreviation for the ethical, legal, and social implications of human genome research.
- **Eugenics:** An early twentieth century movement which aimed to improve the human race by preventing "unfit" people from reproducing (negative eugenics) and encouraging "fit" people to reproduce (positive eugenics). Eugenics was implemented in United States, the Nordic countries, and Germany. The eugenic philosophy is most widely known for the association with Nazi abuses and “better baby” and “fittest family” contests.

- **Exercise-induced asthma:** Asthma symptoms that appear during or following exercise. Symptoms may be minimal or severe enough to require emergency treatment. Some people who have chronic asthma have exercise as a trigger. Some people only develop bronchoconstriction (asthma symptoms) when they exercise.
- **Family health history:** Reflects a family's shared genetics, environment, culture, lifestyle, and behaviors. These combined factors affect a person's risk of developing disease.
- **First-degree relative:** An immediate family member such as a parent, sibling, or child.
- **Gene:** The basic unit of hereditary information passed from parent to offspring.
- **Gene-environment interaction:** The effects of one or more genes interacting with environmental factors in determining the occurrence of disease.
- **Gene-gene interaction:** The interaction of several different genes in the production of a disease.
- **Genetic counseling:** Provides patients and their families with education and information about genetic-related conditions and helps them make informed decisions.
- **Genetic discrimination:** Prejudice against those who have or are likely to develop an inherited disorder.
- **Genetic profile:** The particular arrangement of genes and markers in the DNA, unique to each individual.
- **Genetics:** The study of biological variation. Typically refers to a single gene and its effects.
- **Genetic screening:** Testing a *group* of people to identify individuals at high risk of having or passing on a specific genetic disorder.
- **Genetic testing:** Testing done by analyzing DNA to determine if an *individual* has certain mutations associated with an inherited condition.
- **Genome:** All of the DNA contained in an organism or a cell.
- **Genomics:** The study of all the genes and how they interact with each other and the environment.

- **Human Genome Project:** An international research project to map each human gene and to completely sequence human DNA, completed in 2003.
- **Informed consent:** Obtaining permission to do genetic testing. One must have knowledge of the risks, benefits, effectiveness, and alternatives to testing in order to understand the implications of genetic testing.
- **Inhaled corticosteroid:** Steroidal anti-inflammatory medication useful for people who have asthma. The medication is breathed in through the mouth into the lungs. Also called “ICS”. Not the same as anabolic steroids.
- **Inhaler/meter-dose inhaler (MDI):** A device used to deliver a variety of commonly prescribed asthma medications that help ease breathing by opening the airways.
- **Inherited:** Traits transmitted from parents to offspring.
- **Irritant:** Any substance that causes swelling of the respiratory system. An irritant may trigger asthma symptoms, but they may not be considered an allergen. Examples of irritants include tobacco smoke, chemicals, pesticides or air pollution.
- **Mucus:** Often called phlegm or sputum, this sticky fluid is produced by the membranes lining the airways. Exposure to certain triggers can increase mucus production. Excessive amounts of mucus make breathing more difficult.
- **Multifactorial:** A trait or disease resulting from interplay between multiple genes and environmental factors.
- **Mutation:** A permanent change in DNA. Some mutations can have no effect, can be beneficial, or cause harm to the organism.
- **Nebulizer:** A small, portable machine used to deliver certain asthma medications. It makes a mixture of liquid medicine and water into a mist that a person then inhales through a mask or a mouthpiece. They are often used for babies and children who are too small to coordinate using a MDI. They are also used for those having severe asthma symptoms, as it is easier to take in the medicine this way when having trouble breathing.

- **Newborn screening:** A public health screening program to screen every baby in the United States within the first few days of life, to look for inherited metabolic disorders.
- **Peak flow meter:** A small, portable hand-held device that measures how well the lungs are able to expel air, allowing people with asthma to detect airway narrowing and adjust medications accordingly.
- **Pedigree:** Diagram of a family's genealogy that shows family members' relationships to each other and how a particular trait or disease has been inherited.
- **Personalized medicine:** The development of drug therapies intended to treat people as individuals.
- **Pharmacogenomics:** The study of how an individual's genetic makeup affects their response to drugs.
- **Polymorphism:** A variation in the sequence of DNA among individuals found in at least 1% of the population.
- **Predictive testing:** Genetic testing to identify people who are at an increased risk for developing a certain type of disease or disorder.
- **Privacy:** The rights of individuals to keep personal information secure.
- **Pulmonary function testing (PFT's):** A series of tests used to determine whether a person has breathing problems, and precisely what those problems are. These test lung function and capacity. They do not hurt, as they involve tests that include holding your breath, blowing into a tube as hard as you can, and exercising while wearing a special mask.
- **Quick relief or rescue medications:** Medication taken to relieve asthma symptoms. Called "quick relief" because they can act immediately to reduce symptoms that appear suddenly.
- **Relative risk:** The chance of developing a specific disease as compared to the risk for another individual or group.
- **Second-degree relative:** A relative such as your grandparent, grandchild, uncle, aunt, niece, nephew, or half-sibling.
- **Single gene disorder:** A disorder caused by mutations within one particular gene (Example: Huntington's disease, Tay-Sachs).

- **Single Nucleotide Polymorphism (SNPs):** Pronounced “snips”. A DNA sequence variation that is one base long, and that occurs in at least one percent of the general population. SNPs account for much of the variety among humans.
- **Spacer:** A device that attaches to an inhaler (MDI) by a plastic chamber on one end and a mouthpiece on the other end. It is intended to help medicine from an MDI get into the lungs. A spacer works by holding the medicine in its chamber long enough for a person to inhale it in one or two slow deep breaths. Without a spacer much of the medicine in an inhaler “puff” is deposited on the tongue or in the back of the throat.
- **Spirometry:** Test for diagnosing asthma. A spirometer is an instrument that measures the maximum volume you can exhale after breathing in as much as you can. Small spirometers are available for home use, although peak flow meters are more appropriate for most people.
- **Third-degree relative:** A relative such as great grandparent, great uncle/aunt, or cousin.
- **Trigger:** Anything that causes asthma symptoms to worsen in a given person. Different things are triggers for different people. Some common triggers include exercise, cigarette smoke, pollen, dust, cold air, and upper respiratory infections.
- **Utah Genetic Testing Privacy Act:** This law protects Utah citizens from genetic discrimination in employment and some health insurance settings (To read the law visit <http://www.code-co.com/utah/code/03/26-45.htm>).
- **Wheezing:** A whistling sound that occurs when air moves through narrowed or tightened airways. May be heard on exhalation. Wheezing is a classic symptom of asthma.

References:

- American Medical Association, Medical Library
- Asthma and Allergy Foundation of America
- Baylor College of Medicine
- Human Genome Project Information, Department of Energy
- Lawrence Berkeley National Laboratory’s ELSI Project
- National Coalition for Health Professional Education in Genetics
- National Center for Health Education
- National Human Genome Research Institute, National Institutes of Health,
- University of Utah Genetic Science Learning Center
- University of Virginia, Health System
- Utah Department of Health, Asthma Program, Winning with Asthma